Relationships of Health Behaviors with Stigma and Quality of Life Among Adolescent and Young Adult Patients with Cystic Fibrosis

Honors Research Thesis

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Abstract

Although new medications and treatments for Cystic Fibrosis (CF) have been developed during the past 20 years, behavioral components of medical treatment for CF have been relatively unexplored in prior research. Behavioral components that are critical for optimal health include compliance with medications and dietary recommendations, and regular physical exercise. Physicians prescribe treatment regimens to patients with CF, but relatively little is known about factors associated with performing the prescribed health-related behaviors. Of particular interest are psychosocial factors that may influence behavioral compliance including self-efficacy (perceived ability to adapt to disease), perceived stigma (influence of perceived negative reactions from peer group), and quality of life (adaptation to illness in both mental and physical domains). It was hypothesized that patients who exercise regularly, adhere to medications and treatments, and maintain healthy dietary habits would report higher quality of life, less perceived stigma, and better overall health than those who were not compliant with behavioral recommendations. Fifty adolescents and young adults (mean age = 19.2 years; age range: 15 to 25 years) with CF were recruited from an outpatient hospital-based clinic. Participants completed self-report measures of self-efficacy, stigma, and quality of life, as well as measures of compliance with prescribed medications, exercise behavior, and dietary behavior. Higher self-reported medication adherence was associated with better overall quality of life ($r=0.27$; $p= 0.059$). In addition, perceived stigma was associated with greater

levels of activity (r=0.37, p=0.013). Thus, there was a trend for adherence to be associated with better quality of life. Surprisingly, greater levels of activity were associated with more perceived stigma. However, this may result from active individuals being exposed to more experiences with peers that may be stigmatizing. It will be important to identify strategies to help reduce or avoid perceived stigma among active patients with CF.

Introduction

Cystic Fibrosis (CF) is a life-threatening genetic mutation occurring on chromosome 7 (Gene Gateway, 2003) that affects primarily Caucasians. However, this genetic disease is becoming more prevalent in other ethnicities, such as Hispanics and African Americans. There are roughly 30,000 Americans living with Cystic Fibrosis. This mutation results in progressive respiratory deterioration that results from mucus inspissation in the air. The disease also has negative effects on the pancreas, where inspissated mucus blocks pancreatic ducts, preventing natural digestive enzymes from being released into the intestine effectively. Thus, poor growth and weight gain are common among CF patients despite a calorie dense diet. The reproductive system – especially of males – also is negatively affected. The disease has historically been highly lethal, with the normal lifespan of an individual with CF being less than 10 years in the 1950s. However, expected lifespan has dramatically risen since then with the predicted mean lifespan presently in the upper-30s for individuals with the disease (Cystic Fibrosis Foundation, 2009), and with individuals with CF living into their 50s and 60s. This increase in lifespan is due to advancements in medication and therapies, all of which require adherence and self-monitoring.

Patients with CF typically are given various treatments to follow (e.g. albuterol, tobramyacin, hypertonic saline, physical therapy) in order to expel mucus secretions produced, combat airway infection, and preserve lung function. Nebulized treatments are liquid medications that are inhaled into the lungs. Physical treatments consist of pulmonary percussion that can be achieved in

several ways, such as cupping the hand and pounding the front and back of a patient in order to loosen mucus in the lungs. In addition, there is also a machine that accomplishes this more effectively than pounding with the hand. Patients are also given enzyme tablets to assist the pancreas in digesting food, and there are vitamins prescribed for patients to ensure that daily doses of vitamins are ingested. Most recently, exercise has become a treatment for controlling CF. Taking part in organized regimens of light-to-moderate exercise (e.g. walking, stationary bicycling, light weight-lifting) has proven beneficial for patients with CF (Mayo Clinic, 2008).

Adherence to medication is paramount to treatment of most diseases. In order to successfully adhere to medications, individuals must comply in a cooperative way with the physician or health care provider to the prescribed medications (Taddeo, Egedy, Frappier, 2008). The extensive treatment regimens required of patients with CF unfortunately may decrease the likelihood of adherence (Zemanick, et al. 2009). Control of CF requires taking many different medications. The education level of patients and their families can also influence adherence rates. Patients and families with lower education may fail to recognize the importance of adherence to medications in the presence of a deadly disease, and this may lead to advanced disease progression (Zemanick, et al. 2009). CF adolescents are faced with the greatest adherence challenges due to already being under significant academic and social strains as adolescents. Academic and social stresses are often the most salient stressors in standard adolescent

life, but these strains are augmented in adolescents with CF due to pulmonary treatment demands (Zemanick, et al 2009).

Exercise and diet also are important to patients with CF. Maintaining a healthy diet and consistent exercise program can produce greater lung function and increased cardio-respiratory system function (Wilkes et al 2009). Patients with CF achieve the same benefits from exercising as their healthy peers without CF. Patients who consistently adhere to exercise routines show greater lung function and report a better quality of life (Wilkes et al 2009). Maintaining a strict, calorie-dense diet has positive effects on patients with CF. Optimal nutritional intake can yield better growth, lung function, and greater rates of survival (Stark, Opipari-Arrigan, Quittner, Bean, & Powers, 2010).

Patients with CF report feeling little control over CF facilitated treatment adherence schedules provided by physicians (Abbott, Dodd, & Webb, 1996). Thus, patients with CF do not feel as though they have control over the treatments they are given and the procedures for following them. However, adult patients with CF who follow prescribed dietary measures report higher self-efficacy (i.e. positive feeling of control over one's self) and improved nutritional status (Watson, Bilton, Truby, 2008). CF adolescents who participate in exercise training programs have experienced beneficial effects in oxygen consumption, muscle force, and improved self-efficacy (Gulmans, Meer, Brackel, Faber, Berger, Helders, 1999). Research suggests that exercise training and its benefits contribute to improved self-efficacy and overall quality of life.

However, there are unique obstacles in treating adolescents with CF due to developmental changes in growth and psychosocial functioning that normally occur in adolescence. These extreme changes during adolescence may require novel approaches by doctors in prescribing new medications and treatments to adolescents with CF (Segal, 2008). Adolescents and adults with CF have rates of depression/anxiety ranging from 29%-46% (Zemanick, et al. 2009). Patients with CF who have anxiety and depression have worse lung function and more prominent symptoms of the disease than those patients without anxiety and depression (Cruz, Marciel, Quittner, & Schecter, 2009). It has been found that adolescents with CF are more affected by anxiety, as reflected in a significant negative correlation between anxiety and lung function (Bregnballe, Thastum, & Schiøtz, 2007). In addition, adherence may be significantly affected by anxiety and depression. Feelings of low motivation and stress may be induced by depression and anxiety and are related to poor adherence (Cruz, Marciel, Quittner, & Schecter, 2009). Anxiety and depression also contribute to a lower quality of life in patients with chronic diseases. CF adolescents, however, have the greatest possibility of having anxiety and depression affect both physical and mental health factors (Cruz, Marciel, Quittner, and Schecter 2009). During these years, the adolescent may experience different phases of attitudes toward the disease and how it should be managed.

Relationships with peers are established and reinforced during adolescence, and it is also common to experience academic pressure to succeed. However, transient attitudes displayed by adolescents with CF may

result in perceived stigma. Stigma is defined as feeling as though one is discriminated against, isolated, or rejected by peers due to a defining characteristic. Goffman (1963) classified stigma into several different categories, one of which is a “spoiled identity” that can include having a shortened life expectancy or having a genetic condition that may result in undesirable personal characteristics, which is particularly applicable to CF patients. The “undesirable characteristics” of CF would be the consistent cough and poor caloric absorption, which results in a thin physical appearance that may make patients feel self-conscious and further isolate them from their peers. The need to take pills in public, such as enzymes with meals, or using an inhaler in front of peers also may cause patients with CF to withdraw from their peers. There have been few studies exploring the effects of stigma on populations with chronic illnesses, and no prior studies have evaluated patients with CF. However, Pizzignacco, de Mello and de Lima (2010) found in a recent study that adherence to daily therapies may be reduced due to interference with social activities with peers. Demands of therapies can create a feeling of isolation as well as contribute to perceived stigma among patients with CF, especially in the adolescent population with CF. Experiencing stigma during adolescence could drastically influence how adolescents with CF cope with their disease. Feeling cast out from their peer group may cause these individuals to not adhere to medications and treatments in order to fit in with their peers.

Patients with CF may experience resentment toward the disease, and adolescents especially may feel that the disease should not be affecting them. As

a result, they may proceed to live as though it is not affecting them (i.e., not adhering to medications and therapies). By not following these routines, patients with CF risk experiencing a decline in pulmonary function, a drop in weight, and overall deterioration of physical function. The majority of adolescents with CF begin adolescence with normal lung function and good nutrition, primarily due to the role of the parents. After adolescence, along with natural factors, the health of many CF patients rapidly declines due to decreased role of the parents, who attribute a greater role of responsibility to their children.

This cross-sectional study is designed to evaluate factors associated with self-reported treatment adherence among adolescent and young adult (15-25 years) patients with CF. This study examines correlations of adherence (to medications, diet, and exercise regimens/routines) with perceived stigma, anxiety/depression, and overall quality of life. It is hypothesized that patients with greater overall adherence will report lower perceived stigma, lower anxiety/depression, and higher overall quality of life.

Methods

Participants

Fifty adolescent and young adult patients with Cystic Fibrosis (CF) were recruited from the Cystic Fibrosis Clinic at Nationwide Children's Hospital, Columbus, Ohio during regularly scheduled appointments. The sample size of the population of target patients at Nationwide Children's Hospital is over 140 active patients. The majority of the sample is Caucasian, as that is the group

most affected by the disease. Males and females were recruited in approximately equal numbers, as shown in Table 1.

All patients signed informed consent. Patients 18 years and older signed an independent consent form, and those under 18 years required a parent or guardian to provide written consent.

Upon consent, patients were provided with a questionnaire packet that included measures of demographics, adherence, depression/anxiety, mastery, optimism, stigma, and a CF-specific quality of life questionnaire. Body mass index (BMI), number of recent hospitalizations, and co-morbid conditions were obtained from patient medical records.

Upon completion of the survey, participants received a $5 Target gift card.

Measures

Medications and Therapy Adherence

A self-report questionnaire measuring adherence was developed for the study. Patients reported amount of time prescribed for both physical and nebulized treatments and also reported the amount of time spent adhering to the prescribed treatments. Self-reported time was then divided by the prescribed time to provide a percent-value reflecting adherence. Adherence was calculated for both nebulized medication and physical therapy. Participants also reported adherence to prescribed diets and dietary supplements prescribed by physicians as well as their confidence in being able to successfully adhere to the medications over the span of several weeks. Adherence scores were calculated for physical therapy adherence (e.g. Vest adherence) and nebulized adherence

(e.g. inhaled treatments), as well as dietary supplements (e.g. vitamins and enzymes) measured in two separate scores.

Physical Activity

Physical activity was assessed with a 7-day activity record (Blair, Haskell, Ho, 1985). Activities were categorized as mild, moderate, or intense physical activity, with examples of each category provided to respondents. Participants marked the level of activity performed each day and the amount of time spent performing the physical activity. Confidence in performing physical activity was also recorded as a measure of self-efficacy.

Physical and Social Activity

Amount of physical and social activity was measured using a questionnaire developed for this study. Participants were given a list of activities, classified as social ("hanging out" with friends, doing well academically, having hobbies, extracurricular activities) or physical (playing sports, taking family vacations, having a job, camping). Participants then indicated on a Likert scale from 1 to 4, how much they were impeded from these activities due to CF. A total score was computed from all ratings (with Not Applicable being a zero). Two subscores also were computed to reflect social and physical activities.

CF specific Quality of Life

The Cystic Fibrosis Questionnaire-Revised (CFQ-R; Quittner, Buu, Messer, Modi, & Watrous, 2005) was included to assess physical, social, and emotional aspects of CF, treatment burden, and health perceptions. The measure is designed for CF patients age 14 and older.

Anxiety and Depression

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was used to measure symptoms of depression and anxiety. The measure includes 7 self-report items assessing anxiety and 7 items assessing depression. Each item is rated on a 4-point Likert scale.

Mastery

Perceived control was measured with Pearlin and Schooler's (1978) seven-item Personal Mastery Scale. Each of the seven statements is rated on a 4-point Likert scale, ranging from 0 (Strongly Disagree) to 3 (Strongly Agree), with some items reverse scored.

Stigma

Fife and Wright's (Fife & Wright, 2000) Social Impact Scale (SIS) includes 24 items evaluating stigma among patients coping with a chronic illness. A total score and four subscale scores are calculated: social rejection, financial insecurity, internalized shame, and social isolation. The financial insecurity subscale was modified to reflect academic insecurity because most participants were attending an academic institution during the study. Each item on the scale is rated on a four-point Likert scale ranging from 1 (Strongly Disagree) to 4 (Strongly Agree) and also includes a "not applicable" option.

Data Analysis

Data were analyzed with Pearson correlations and analyses of variance (ANOVAs). Correlations examined the relationship of treatment adherence and confidence to quality of life, stigma, anxiety, depression, mastery, and overall

activity. To evaluate the relationship between illness severity and outcomes, the sample was divided into two groups: less severe patients with FEV1% predicted at or above the 80th percentile vs. patients with more severe illness. ANOVA was then conducted for adherence measures and other psychosocial variables using illness severity as the between subjects factor.

Results

Nebulized (e.g. inhaled medications) adherence was positively correlated with physical therapy adherence ($r = 0.58$; $p < 0.001$) and enzyme adherence ($r = 0.34$; $p = 0.017$), as well as negatively correlated with the HADS total ($r = -0.31$; $p = 0.037$), and with the anxiety subscale ($r = -0.32$; $p = 0.023$), as shown in Table 2. Overall, stigma was not associated with nebulized treatment adherence. However, analysis of subscales indicated that the financial/academic insecurity was negatively correlated with nebulized adherence ($r = -0.33$; $p = 0.020$). Nebulized adherence was not associated with quality of life or mastery.

Physical therapy adherence was not significantly correlated with any psychosocial variables, but was correlated with enzyme ($r = 0.42$; $p = 0.003$) and diet ($r = 0.34$; $p = 0.021$) adherence. Physical therapy adherence was positively associated with confidence in engaging in physical activity ($r = 0.34$; $p = 0.019$).

Dietary adherence was not correlated with any other variables. Exercise adherence also was not correlated with psychosocial variables.

Total activity (social and physical combined) was negatively correlated with several CF quality of life measures, physical ($r = -0.33$; $p = 0.026$), emotional ($r = -0.39$; $p = 0.007$), and treatment ($r = -0.35$; $p = 0.017$), as shown in Table 3.

Thus, greater activity was associated with worse quality of life in physical, emotional, and treatment burden domains. Total activity was correlated with HADS total score ($r = 0.34$; $p = 0.027$) and with the anxiety subscale score ($r = 0.32$; $p = 0.031$). Subscale analyses indicated that social activity was associated with anxiety ($r = 0.38$; $p = 0.008$), and with depression ($r = 0.30$; $p = 0.047$). Total activity also was associated with SIS total ($r = 0.32$; $p = 0.03$), as shown in Table 4. Among SIS subscales, only social rejection was associated with activity ($r = 0.35$; $p = 0.019$).

Physical quality of life was associated with less social rejection ($r = -0.49$; $p = 0.0004$), less financial/academic insecurity ($r = -0.35$; $p = 0.012$), and less social isolation ($r = -0.44$; $p = 0.00014$). Emotional quality of life was associated with less social rejection ($r = -0.45$; $p = 0.0013$), less financial/academic insecurity ($r = -0.49$; $p = 0.0003$), and less social isolation ($r = -0.67$; $p = <0.0001$). Social quality of life was associated with less social rejection ($r = -0.49$; $p = 0.0003$), less financial/academic insecurity ($r = -0.31$; $p = 0.029$), less internalized shame ($r = -0.42$; $p = 0.0026$), and less social isolation ($r = -0.56$; $p = <0.0001$). Total activity also was associated with social rejection and financial/academic insecurity (dimension 1) of the SIS scale ($r = 0.37$; $p = 0.013$).

Self-reported confidence in performing nebulized and physical therapy revealed a positive correlation ($r = 0.86$; $p < 0.0001$) with nebulized adherence. Reported dietary confidence also was associated with enzyme and vitamin adherence confidence ($r = 0.48$; $p = 0.003$).

Exercise confidence was positively associated with perceiving one's health as being better than that of peers without CF ($r = 0.39$; $p = 0.005$) and that of peers with CF ($r = 0.40$; $p = 0.004$). Greater exercise confidence also was associated with lower HADS total score ($r = -0.63$; $p < 0.0001$), and with lower anxiety ($r = -0.33$; $p = 0.019$) and depression ($r = -0.75$; $p < 0.0001$), as well as lower stigma ($r = -0.32$; $p = 0.029$). Greater experienced and perceived stigma were associated with lower exercise confidence. In particular, social rejection was associated with lower exercise confidence ($r = -0.34$; $p = 0.019$). Greater exercise confidence was associated with higher CF quality of life - emotion ($r = 0.45$; $p = 0.001$), with social quality of life ($r = 0.51$; $p = 0.0001$), and with CF quality of body ($r = 0.44$; $p = 0.001$), physical ($r = 0.60$; $p < 0.0001$), and vitality ($r = 0.60$; $p < 0.0001$).

As shown in Table 5, participants with less severe disease, indicated by FEV1% scores at or above the 80th percentile, had significantly higher scores on CFQ-R physical ($p = 0.008$), vitality ($p = 0.036$), and body ($p = 0.013$). However, there were no illness severity differences in CF quality of life subscales of emotion, social, diet, and treatment burden. In addition, there was no group difference in stigma or in nebulized or physical therapy adherence. There was a trend on depression ($p = 0.095$) indicating that patients with less severe disease report less depression than those with more severe disease. However, there was no group difference for anxiety. Patients with less severe disease are more likely than patients with more severe disease to view their health as good as or better than peers their age without CF ($F = 15.96$, $p = 0.0002$) and compared to peers

with CF ($F = 24.87$; $p < .0001$). Exercise confidence also demonstrated a trend reflecting that patients with less severe disease appeared to have greater exercise confidence than others ($F = 3.73$, $p = 0.059$). There was no illness severity effect for enzyme and vitamin adherence.

Discussion

Self-reported treatment adherence, both to physical therapy and medications, was associated with better self-reported physical functioning. This may be a result of the treatment effects on the lungs and other treatment target areas (e.g. pancreas, sinuses, bowels), allowing individuals to feel less fatigued. Adherence to medication was associated with less anxiety and less financial/academic insecurity. Adhering to medication may cause patients to display fewer symptoms, decreasing the chance that they display aspects of CF that may cause anxiety or insecurity. However, treatment adherence was not associated with CF-specific quality of life measures. Although it was expected that medication adherence would be associated with fewer symptoms of CF and thus be associated with a more “normal” life and better quality of life, the results did not support the hypothesis. Adolescent asthma patients have been studied, reporting that the more asthma symptoms one had, the greater the levels of anxiety experienced (McGrady, et. al., 2011). These findings may indicate that treatment and screening for anxiety may result in improved treatment adherence and decreased anxiety. Addressing this finding in CF patients may also result in improved treatment adherence and decreased anxiety.

Nebulized adherence was associated with less anxiety and depression. The effects of nebulized adherence (i.e. creating cleaner airways and reduced pulmonary obstructions) may cause individuals to be less anxious around peers and also feel better about their health as a result of the medication. Although physical therapy adherence was not associated with anxiety or depression, it may be that other forms of physical therapy (e.g. running, weight training, sports) may have a greater association with anxiety and depression. Diet adherence was not associated with anxiety or depression. Exercise confidence also was associated with less anxiety and depression. Higher self-efficacy regarding the performance of exercise and sports may reduce anxiety and depression amongst individuals with CF because the capability to perform exercise may indicate that individuals with CF are at the same level as their peers without CF. Overall activity level was positively correlated with anxiety and, to a lesser degree, with depression. Increased activity may be associated with anxiety and depression due to patients taking part in physical and social activities among peers without CF. This may, in turn, lead to patients feeling self-conscious about performing any CF related behavior (e.g. coughing up mucus, taking enzymes, puffing inhaler) in front of peers, thus contributing to anxiety around friends. Depression may result from active individuals with CF perceiving differences between themselves and their peers without CF. However; patients who are naturally inclined toward anxiety may feel compelled to engage in more activity. The association with anxiety and depression was of greater magnitude in the domain

of social activity. This may be due to more regular comparisons being made during social activity.

Lower financial/academic insecurity was associated with greater nebulized adherence. This indicates adherence to nebulized treatments may have a positive influence on financial/academic insecurities. Physical therapy adherence and dietary adherence were not associated with stigma. This result may exist because the diet and some physical therapy (e.g. exercise) are the same as individuals without CF. Stigma was negatively correlated with exercise behavior confidence, indicating that increased exercise confidence was associated with decreased perceived stigma. This relation demonstrates a possibility that patients who believe they have the capacity to perform physical activity experience less negative judgment from their peers. The social rejection variable was negatively correlated with exercise confidence as well; indicating that greater confidence in performing exercise behavior was associated with less social rejection. With increased social confidence around peers, individuals with CF may not feel as though peers are as likely to stigmatize them. Surprisingly, total activity was associated with greater stigma. It is possible that active CF patients experience more opportunities for being judged by their peers without CF. Total activity was associated with reduced CF quality of life (physical, emotional, and treatment) demonstrates this point. Increased interaction with peers may lead to feeling inadequate compared to peers, thus promoting a decrease in quality of life. Also, more activity performed by CF patients may lead to less time allotted for medication, which may be the cause for the decrease in treatment burden

reported by participants. These results are similar to those seen in modern asthma studies, in which adolescents with asthma had much greater social anxiety than peers without asthma. Bruzzese et al. (2009) found that adolescent asthma patients had increased anxiety in social settings and feared social rejection and isolation for any medical symptoms and/or behaviors. These findings may suggest common sources of anxiety in both CF and asthma adolescents. Preventative measures that have been developed to address social anxiety in adolescent asthma patients may be useful among adolescent CF patients as well.

Adhering to medications was expected to be associated with a better quality of life because the disease can be devastating without proper treatment. However, performing medical procedures to remain healthy may generate a feeling of discontent, therein producing a lower quality of life. Diet was not significantly correlated with CF specific quality of life. CF specific quality of life correlated positively with exercise behavior confidence, showing that greater confidence in ability to engage in physical activity is related to better quality of life. CF quality of emotion (feelings of emotional health) was positively correlated with exercise confidence. Perhaps individuals with CF who feel capable of performing exercise have an enhanced emotional quality of life due to feeling that they can take action in the context of the illness. Exercise confidence was also associated with CF social quality of life. Thus, exercise confidence may also reflect or facilitate access to social relations. CF quality of life measures of body, physical, and vitality all were associated with exercise confidence. Thus having

confidence in exercise abilities appears to be related to better body image and greater physical quality of life. The ability to perform exercise and the execution of exercise are associated with a better sense of overall vitality in daily life as well.

There are several limitations of this pilot study. The measure of adherence was the greatest limitation. Creating a measure that more accurately records both nebulized and physical therapy adherence would be important. The current study relied on self-report from memory, which is subject to reporting bias. Also, correlations with dietary adherence may have been limited due to few CF patients in the study having a prescribed diet.

Future studies to further examine the results and implications of this study may promote further understanding. Examining whether treatment for anxiety influences nebulized treatment adherence may indicate to physicians that addressing anxiety is a way to improve nebulized adherence. The association between social activity and distress (i.e., anxiety, depression, and experienced stigma) may result from patients being more exposed to circumstances of social distress or social comparison. Addressing the influence of social activity and positive social interactions may reduce feelings of anxiety and depression and experienced stigma. Reducing stigma may occur by encouraging patients to talk to peers about specific aspects of the disease that may be salient in relationships with peers. Thus, the goal would be to prevent any perceived thoughts of stigma, which may result from the perception that peers do not understand the disease. Confidence and mastery may also be important intervention targets for improving

adherence and quality of life and reducing feelings of anxiety and depression and stigma. Providing ways to maintain confidence under conditions that elicit feelings of anxiety and depression may improve quality of life of patients with CF.

Overall, the data indicate important associations to consider in the care of patients with CF. Physicians may want to make patients aware of the positive associations with adhering to prescribed medications. Treating patients with anxiety and depression may help promote better adherence among affected patients by helping patients feel less negative about performing medical therapies. This may cause patients to be more adherent to treatments, potentially leading to a better overall quality of life. By performing medications at home and talking with peers about CF, individuals may also find that performing activities with friends will not result in greater perceived stigma. Having a good quality of life, low anxiety and depression, and low perceived stigma is paramount to enhanced life quality. By promoting treatment adherence, physicians may influence young patients with CF to realize that medications do not need to detract from doing other activities, but provide a long-term way of enhancing life and creating the healthiest life achievable for the individual.

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Table 1. Demographics of Sample

(n = 50)

	n	%
Male	27	54.0
Living with Parents	34	68.0
	Mean	Sd
Age Range: 15-25	19.2	3.1
FEV1% Predicted	78.0%	24.6

Table 2. Correlation of psychosocial variables with adherence to two therapies		
	Nebulized	Physical Therapy
Anxiety	-0.323*	-0.128
Depression	-0.177	-0.258
Social QoL	0.160	0.119
Physical QoL	0.135	0.191
Emotional QoL	0.246	0.159
Dietary QoL	-0.138	-0.076
Treatment QoL	0.016	-0.110
Experienced Stigma	-0.195	-0.192
Perceived Stigma	-0.124	-0.009
Mastery	0.151	0.013

* p< 0.05	** p< 0.01	*** p< 0.001

Table 3: Correlations of activity dimensions and confidence with psychological variables

	Activity	Social Activity	Physical Activity	Confidence
Anxiety	0.323*	0.380**	0.230	-0.332*
Depression	0.249	0.298*	0.183	-0.754***
Social QoL	-0.219	-0.128	-0.251	0.508**
Physical QoL	-0.329*	-0.245	-0.355*	0.601***
Emotional QoL	-0.393**	-0.315*	-0.380**	0.446**
Dietary QoL	0.037	0.142	-0.077	0.357*
Treatment QoL	-0.351*	-0.175	-0.458**	0.182
Body QoL	-0.269	-0.204	-0.240	0.442**
Vitality	-0.125	-0.059	-0.195	0.598***
Mastery	-0.063	-0.149	-0.013	0.249

* p< 0.05	** p< 0.01	*** p< 0.001

Table 4. Correlations of stigma with activity dimensions, quality of life, and adherence

	Experienced Stigma	Perceived Stigma	Social Rejection	Internalized Shame	Social Isolation	Financial/ Academic Insecurity
Social Activity	0.303*	0.110	0.277	0.054	0.120	0.253
Physical Activity	0.333*	0.242	0.348*	0.084	0.280	0.192
Physical QoL	-0.511***	-0.360*	-0.494***	-0.098	-0.440**	-0.351*
Emotional QoL	-0.547***	-0.566***	-0.452**	-0.198	-0.666***	-0.487***
Social QoL	-0.496***	-0.589***	-0.499***	-0.418**	-0.565***	-0.308*
Mastery	-0.284	-0.562***	-0.279	-0.454**	-0.524***	-0.199
Exercise Confidence	-0.307*	-0.297*	-0.338*	-0.085	-0.360*	-0.147
Physical Adherence	-0.192	-0.009	-0.164	0.107	-0.077	-0.168
Nebulized Adherence	-0.195	-0.124	-0.071	-0.018	-0.182	-0.331

* p< 0.05	** p< 0.01	*** p< 0.001

Table 5. Quality of life and adherence by illness severity

	Normal Range (FEV1% ≥ 80%)	Impaired Range (FEV1% < 80%)
Treatment QoL	55.1 (22.1)	52.5 (17.8)
Dietary QoL	92.4 (13.5)	85.8 (18.3)
Social QoL	74.5 (18.2)	68.2 (18.7)
Emotion QoL	75.5 (18.4)	70.8 (23.8)
Physical QoL	84.1 (16.8)	65.9 (26.7)**
Vitality QoL	62.1 (16.2)	51.2 (19.3)*
Body QoL	77.3 (18.9)	59.8 (27.3)*
Exercise Confidence	87.8 (16.9)	74.2 (29.4)
Self-rated health compared to		
Peers with CF	2.8 (0.40)	1.9 (0.70)***
Peers without CF	1.91 (0.68)	1.24 (0.51)***

* p< 0.05	** p< 0.01	*** p< 0.001